TRANSFORMING THE DIABETES JOURNEY – adopting a life course approach for citizens' improved well-being and healthcare systems' resilience in the European Union

What is diabetes?

Diabetes is a group of chronic metabolic disorders characterised by **elevated levels of blood glucose**. High blood glucose levels directly cause micro- and macro-vascular complications.

It is a **highly complex condition**, whose onset involves different mechanisms, facilitated by risk factors. The World Health Organization (WHO) recognizes **more than 10 forms of the disease**.



No one is immune to diabetes, which may affect people from all walks of life, at any point in their life.

TYPE 1 DIABETES (T1D) is an auto-immune disease, whereby the body destroys insulin-producing cells (β-cells) in the pancreas. People living with T1D need insulin injections to survive.

TYPE 2 DIABETES (T2D) is the single most common form, accounting for about 90% of all cases. It develops due to a combination of unmodifiable (genetic, physiological, environmental) and modifiable, behavioural risk factors.

GESTATIONAL DIABETES (GDM) is a form of diabetes which develops during pregnancy, when the body does not produce enough insulin to meet the additional metabolic needs of the person giving birth and foetus.

Why should diabetes be a health priority in the European Union (EU)?

Diabetes is a measure of inequalities among EU citizens, which it also exacerbates, as well as a marker of healthcare system resilience



Diabetes represents a huge and growing individual and societal burden

Diabetes is the root cause of many other conditions

Why should diabetes be a health priority in the European Union (EU)?

DIABETES REPRESENTS A HUGE AND GROWING INDIVIDUAL AND SOCIETAL BURDEN

1 in 10 adults
34m people live with diabetes in the EU [1]

1/3 of PwD are **undiagnosed** [1]

Some **200,000 children and adolescents** live with **T1D** in the EU (14% of the world total) [1]

€119bn
Diabetes-related health expenditure (EU, 2024) [1]

3/4 of diabetes costs result from diabetes-related complications [2]

Diabetes leads to productivity losses, undermining EU's competitiveness [3]

GDM increases the risk for the person giving birth and the child to develop **T2D** later in life [4]

Diabetes is increasingly borne by younger generations, **with a rise in young onset T2D (<40yo)** [5]

Diabetes is exacerbated by the **ageing of population** [6]

Diabetes is a **complex condition, rooted in the exposome during PwD's life**, and **compounded by the healthcare ecosystem's response**.

Suboptimal diabetes prevention and management generate **high carbon emissions** [7]

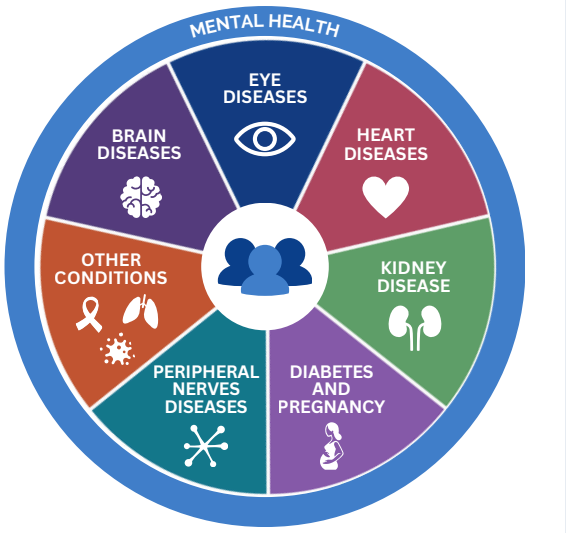
DIABETES IS THE ROOT CAUSE OF MANY OTHER CONDITIONS

Diabetes is a hugely complex condition to manage, requiring **coordination across many specialties and care levels** as well as robust and **constant self-management**.

PRIMARY & COMMUNITY CARE | **SECONDARY CARE** | **TERTIARY CARE**



Cardio-vascular (CVD) and renal diseases, blindness and amputations are some of the direct consequences of its **ineffective management**, and represent the real cost of the disease. The younger a person is diagnosed with T2D, the more serious the complications are likely to be.



[8]

1/3 of PwD develop **CVDs** [9]

80% of **end-stage renal disease** is caused by diabetes/+ hypertension [10]

1/3 of PwD develop **diabetic retinopathy** [11]

Up to 1/2 of PwD have **peripheral neuropathy** [12]

Beyond physical complications, the relentless nature of diabetes management coupled with **stigma** and **discrimination** often create significant **mental health issues** for PwD.

PwD are **2-3x** more likely to experience depression than people without diabetes [13]

Its impact on individuals and healthcare systems is generally underestimated due to **misperceptions** of its seriousness **and low direct mortality**.

DIABETES IS A MEASURE OF INEQUALITIES AMONG EU CITIZENS, WHICH IT ALSO EXACERBATES AND A MARKER OF HEALTHCARE SYSTEM RESILIENCE

The **socio-economic determinants of health** have a disproportionate impact on the risk of developing diabetes and adverse health outcomes.

Other determinants such as sex, gender and age are variables leading to massive **disparities in risks and outcomes**, for example, linked to differing health-seeking behaviours, risk profiles and access to care, which are exacerbated by the lack of dedicated research.

Huge **inequalities** in access to, availability and affordability of, quality care, medicines and treatment exist among and within EU countries, resulting in vastly **differing quality of life and health outcomes for PwD**.

Effective diabetes prevention and management require a comprehensive **health-in-all policies approach** as well as **concerted action** across both social and health care systems. This is contingent on a multi-faceted approach being implemented – targeted research funding and scope, healthcare systems' digitalisation and person-driven integration, adoption of innovative approaches in healthcare delivery as well as innovative medicines, tools and technology, an educated workforce and patient empowerment.



How can the European Union transform the diabetes journey for European citizens' improved well-being and healthcare systems' resilience?

Transforming the diabetes journey is predicated on understanding the close interconnectedness between individual health factors (e.g. genetics), **the exposome** (broader, external influences – social, commercial, economic, and environmental determinants – and the biological response to it) **and the healthcare ecosystem itself** (research, access and delivery) in order to develop a comprehensive health-in-all policy framework, combining public health and individual approaches with a re-think of healthcare delivery systems, supporting person-centred, personalised care across the life course.



It needs to be built through EU-driven action, supported by culturally and settings-adapted national implementation. Such an approach which would consider the broad external environment as well as the person throughout their life, rather than individual conditions in silos, would greatly contribute not only to improving the quality of life and health outcomes of people living with diabetes and other NCDs but also to supporting healthier and fairer environments and reducing the burden on healthcare systems, thereby bolstering their sustainability and resilience.

In so doing, action on diabetes can underpin a move towards a more equitable and sustainable society and be a key driver of social and economic progress.

Transforming the diabetes journey

THE EXPOSOME

Social determinants

- Income & social protection
- Education
- Unemployment & job insecurity
- Working life conditions
- Food insecurity
- Housing
- Early childhood development

Social & community networks

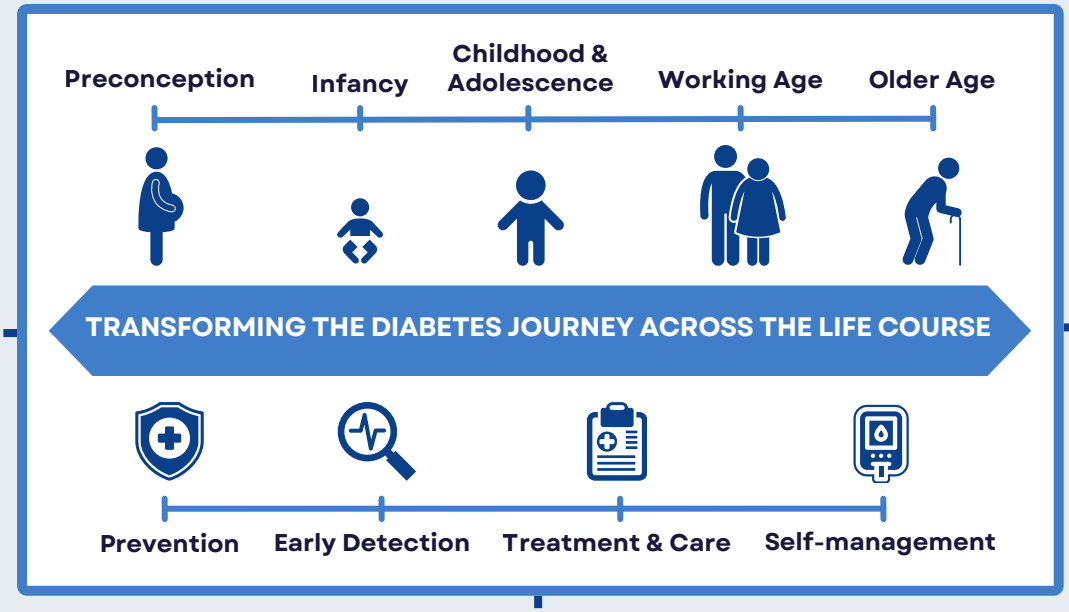
Commercial determinants

Environmental health

- Climate change
- Agriculture
- Environmental stressors
- Physical environment

INDIVIDUAL HEALTH FACTORS

- Genetics
- Prenatal exposures
- Mental ability



HEALTHCARE ECOSYSTEM

Access to care, medicines, tools & technologies

Healthcare delivery

- Organisation of prevention & care
- Personalisation of care
- Empowerment and engagement

Research

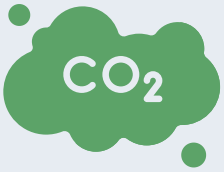
- Basic science
- Translational research
- Behavioural insights

Health equity
Resilience & sustainability
Well-being
Sustainable societies

ADDRESSING THE MAIN DRIVERS OF POPULATION HEALTH – ACTING ON THE EXPOSOME

Environmental health

According to WHO, healthier environments could prevent almost one quarter of the global disease burden.[14] **Environmental health**, which includes the physical environment, environmental stressors and climate change, **has been shown to have a major bi-directional relationship with diabetes and other NCDs, and healthcare systems themselves**. Environmental factors are of two distinct natures – those with a direct impact (e.g. pollution) and those affecting behaviours such as the ability to take physical activity (e.g. pavements, green spaces).



A key environmental stressor, air pollution, for example, is a major risk factor for diabetes. Chronic exposure to particulate matter (PM) of a diameter of 2.5 µm or less **has been linked to one fifth of global T2D cases**,[15] while increased PM2.5, PM10 SO_2 and NO_2 have been associated with an increased risk for GDM.[16]



Another example, heatwaves linked to global warming are responsible for higher rates of hospitalisations in PwD,[17] while they also increase the risk of diabetes.[18]

Unsustainable agriculture, with high usage of chemicals and production of food with lower nutritional values, **also has a clear negative impact on both human health and climate change**.

There is now clear evidence of the link between exposure to pesticides and incidence of conditions such as diabetes.[19] Heavy consumption of highly processed foods combined with food deserts and swamps also negatively affect people's ability to follow healthy diets, themselves a key driver of T2D.[20] This does not only affect younger populations but also older adults as they become less mobile.

Developing policies supporting health-enabling environments, such as healthier built environments, while also addressing the food offering (from better agricultural practices through to food labelling, product composition and taxation) **would go a long way towards lowering the risk of diabetes**.

The healthcare sector, meanwhile, is responsible for about 5% of total global carbon emissions, with care pathways accounting for 40%.[21] **Not only would re-thinking healthcare design and delivery to optimise diabetes prevention and management benefit PwD by lowering the risk of diabetes-related complications but it would also contribute to reducing carbon emissions**, thereby helping address climate change.

Social determinants

Going hand-in-hand with some environmental drivers, the social determinants of health – the conditions in which people are born, grow, live, work and age – also play a strong role in influencing health, and significantly contribute to health inequalities and disparities, which are particularly evident in the context of diabetes.

The social determinants of health are estimated to account for between 30-55% of health outcomes [22]

Poverty is, for example, associated both with higher diabetes incidence and with inequalities in access to diabetes care. Adults in poor and near-poor households have the highest rates of diabetes and low-income populations are more likely to develop the condition.[23] There is a strong correlation between the education level and the development of T2D and diabetes-related complications, which increases as the level of education decreases, placing people with a lower level of education at a 2.4 times higher risk of developing the condition. Most of these factors are intertwined and play a role at all stages of life.[24]

Commercial determinants

Alongside social determinants, commercial sector actors have been a key obstacle to the development of healthier environments – in the case of diabetes, primary linked to food and drinks. The commercial determinants of health – "the systems, practices and pathways through which commercial actors drive health and equity" – play a key role notably through the use of marketing strategies driving (over) consumption of unhealthy product and product composition, e.g. containing high levels of trans-fats or sugar. [25]

PERSONALISING ACTION – UNDERSTANDING DIABETES

Individual health factors

While T1D and T2D have different causes, genetics play a key role in predisposing people to developing the condition in both cases.

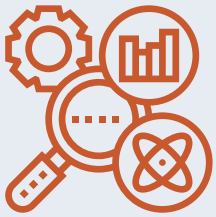
T1D

For T1D for example, the risk for a child of developing the condition when both parents live with T1D is about one in four. Subsequently, a trigger is required for the disease to develop. For T1D, little is known as to what this might be, although various possibilities have been mooted such as exposure to some viruses.

T2D

T2D is a highly heterogenous condition, with significant heritability and broad differences by ethnic groups.[26] Many unknown areas remain relating to disease progression, development of diabetes-related complications and response to medication. A recent study suggested, for example, that T2D could be sub-divided into five distinct clusters, with different clinical characteristics, disease progression and outcomes.[27]

Many new pharmaceutical agents have recently shown much promise in simultaneously managing blood glucose levels as well as protecting various organs from diabetes-related complications. However, further investigation is required to determine optimal usage and identify specific populations that would benefit the most from these treatments, as they differ depending on the specificities of diabetes-related complications, themselves linked to sub-types and other characteristics.



More research is required both to profile and stratify PwD to personalise treatment approaches and to develop the main unmet medical need for diabetes – a cure.

ADAPTING TO THE LIFE COURSE – IMPLEMENTING A CROSS-CUTTING APPROACH

Diabetes health journey

Diabetes is a condition which is life-long and does not currently have a cure. **Health determinants combined with actions and decisions taken at various stages of the life course influence disease progression, quality of life and health outcomes.**



PRECONCEPTION

As well as other external environmental factors, the environment in which the foetus develops has a long-term impact on the person. Hyperglycaemia in pregnancy (HIP), which includes both GDM and diabetes in pregnancy (DIP), which refers to pregnant individuals with pre-existing diabetes, places children born to people with HIP at very high risk of obesity, early onset T2D and cardiovascular disease. HIP perpetuates the risk of diabetes into the next generation.[28]

EARLY SCREENING

Early screening is a prerequisite to identifying people at risk of developing diabetes and potentially lowering their risk to develop the condition, or delaying its onset – both for T2D and in a recent breakthrough, also for T1D.



EARLY ACTION

Early action enabling better management of glucose and other risk factors such as blood pressure and dyslipidaemia (through a combination of lifestyle interventions and/or medication as well as self-management education) is also critical to lowering the risk of future diabetes-related complications and has been shown to have long-term benefits.[29]

This is true for all types of diabetes and at all ages, and is even more critical in youths diagnosed with T2D, for which diabetes-related complications develop earlier and more aggressively.

CHILDHOOD & ADOLESCENCE

During childhood and teenage years, an adapted response to diabetes management is also necessary. This includes the provision of additional psychological support (to manage diabetes burnout and distress, body image and disordered eating, for example) including through peer-to-peer contacts and adequate self-management education.

This becomes all the more important when children and teenagers become more independent, move away from home, and transition from paediatric to adult care.

OLDER ADULTS

An increase in life expectancy combined with earlier T2D diagnoses means not only that older adults form a significant proportion of all people living with diabetes (it is estimated that more than 50% of PwD across Europe are older than 65 years of age, with 25% older than 75), but also their needs may be more complex to meet.

Managing diabetes in older adults requires yet a more targeted approach,[30, 31] considering their settings (home vs retirement centre; social networks), overall health status (e.g. frailty, cognition, mental health), and use/availability of self-management tools, such as digital technologies.

A life-course approach considering PwD's needs in a holistic fashion at key stages of their lives, rather than through a siloed disease-focused approach, is required to optime well-being, health outcomes and quality of life, and reduce inequalities.

TRANSFORMING THE HEALTHCARE SYSTEM RESPONSE – ADAPTING TO NEEDS THROUGH PERSON-CENTRED, INTEGRATED AND INNOVATION-DRIVEN APPROACHES

As was highlighted by the COVID-19 crisis, healthcare systems are ill equipped to deal with chronic diseases, and still operate with a cure rather than prevention mindset. **Adapting to the needs of people living with chronic diseases**, such as diabetes, who often have to deal with more than one condition across the life course, **requires healthcare systems to take a radically different perspective and adopt an integrated, personalised and person-centred rather disease-oriented approach**.

Organisation of prevention and care

Prevention and management must be coordinated across a multidisciplinary team of professionals working across different settings and levels of care along clearly defined care pathways.

General practitioners, diabetes specialist nurses, endocrinologists, diabetes educators, psychologists and other specialists all play a part.

Personalisation of care

The delivery of integrated care is contingent upon understanding PwD's needs and preferences, as the condition evolves and people's circumstances change, for example as they move from paediatric through to adult care.

Digitalisation of health systems

Key enablers of care integration supporting novel care pathways are the improved use of data, the digitalisation of healthcare systems and the use of artificial intelligence (AI), digital tools and digital technologies. Innovations such as telemedicine, apps and medical devices can help deploy better, more personalised care delivery while also leveraging data and the use of AI to support prevention campaigns.



Access to care, medicines, tools and technologies

Another key component of the healthcare system response is its ability to deliver uninterrupted, equitable and affordable access to medicines, technologies and care. Great inequalities persist within and between EU countries. **Barriers to adequate access are numerous.**



Access to the right treatment at the right time and place as well as regular reassessments and screening are, for example, often adversely affected by the current shortage or lack of education of healthcare professionals (HCPs). **An improvement is predicated on strengthening primary care systems and allocating resources more efficiently.**

Another issue relates to the availability and affordability of existing and new medicines and technologies. Dependent on the EU country, this varies widely by age, type of diabetes and ability to pay, while not all medicines/technologies are available in the first place.





Also often lacking is the provision of structured diabetes education at the time of diagnosis and throughout the life course, which is a prerequisite to optimal self-management.

Health-seeking behaviours and access to healthcare is strongly related to a person's gender and circumstances, but also seldom taken into account. **A more concerted approach to providing access to healthcare in a more equitable manner is urgently required, which must include all stakeholders.**

Empowering and engaging PwD – the lynchpin of transformative action

Critical to transforming the diabetes journey is ensuring that PwD are given a voice in everything that affects them – from defining research needs to designing clinical trials protocols, to developing and implementing awareness and education campaigns, to evaluating interventions, medicines and medical devices and participating in reimbursement decisions, and being an equal partner in care decisions.



To deliver on this, a review of governance structures at all levels is required, supported by improved awareness and education for HCPs, PwD and all diabetes stakeholders. **Only through such concerted and comprehensive engagement and involvement can a meaningful impact be made for individuals and the society at large.**

EU POLICY RECOMMENDATIONS

1 ADDRESS THE MAIN DRIVERS OF POPULATION HEALTH

- Improve environmental health
- Address the fundamental determinants of health
- Support health and digital literacy

2 RAISE AWARENESS AND TACKLE INDIVIDUAL MODIFIABLE RISK FACTORS

- Raise awareness from an early age (schools)
- Act at community and primary care levels
- Address stigma and discrimination through guidelines on evidence-based and respectful communication for institutions, HCPs and the general public

3 TRANSFORM HEALTHCARE DELIVERY THROUGH A LIFE COURSE APPROACH AND ACT EARLY THROUGH ADAPTED SCREENING INITIATIVES

- Map and share best prevention practices & define effective screening criteria, approaches and systems for screening of people at high-risk of diabetes and other NCDs
- Explore targeted support and adapted interventions at different stages of people's lives
- Promote access to quality, comparable data across the EU. through the development of registries and a Diabetes and Health Observatory, providing an extensive repository of best practices and approaches to tackling diabetes and other NCDs

4 ENSURE AFFORDABLE AND EQUITABLE ACCESS TO THE RIGHT TREATMENT AT THE RIGHT TIME, IRRESPECTIVE OF GEOGRAPHY, AGE & OTHER PERSONAL CIRCUMSTANCES.

- Develop framework and conditions to guarantee early, affordable and uninterrupted access
- Improve primary HCP training
- Ensure adequate self-management education
- Explore common EU approaches to medicines development and procurement

5 SUPPORT MS IN OVERHAULING NATIONAL HEALTHCARE SYSTEMS, AND FINANCE TRANSITION AND RESEARCH INTO THE MOST EFFECTIVE STRATEGIES TOWARDS:

- Adopt innovation and promote digitalisation
- Develop person-centred, integrated care pathways – at individual disease level and across comorbidities – with strengthened primary & community care
- Draft, implement and monitor national diabetes plans and strategies.

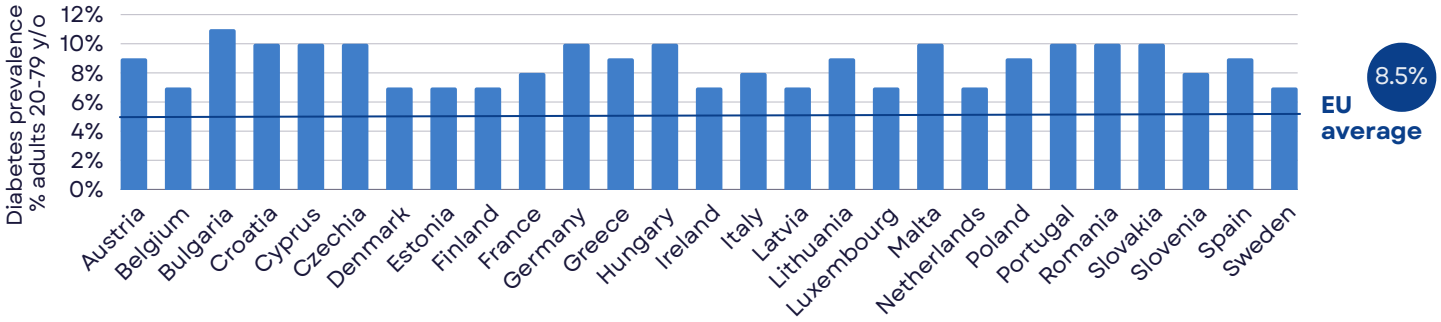
6 ENCOURAGE INNOVATION AND RESEARCH INTO UNMET HEALTHCARE NEEDS

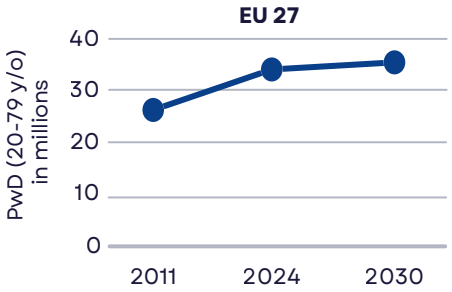
- Boost funding for basic science into the mechanisms of diabetes and the development of more targeted treatments as well as for translational science and behavioural insights
- Set up a Diabetes & NCDs Research Mission, alongside the lines of Europe's Beating Cancer Plan.
- Launch a European Accelerator for Innovation and Digital Transformation, focused on rapidly bringing to market and deploying within the EU national health systems the most advanced and innovative prevention and education initiatives, treatment and care practices for better health outcomes and optimised health.

All of this needs to be supported by full engagement and empowerment of people with lived experience and civil society, embedded as a matter of principle in all legislative, policy and healthcare-related actions.

THE EU DIABETES PREVENTION AND MANAGEMENT LANDSCAPE

DIABETES PREVALENCE





Children & adolescents with T1D (0-19 y/o)

200,000

Diabetes-related deaths **285,000**

People with undiagnosed diabetes

26.4% **(9m people)**

Average expenditure per person

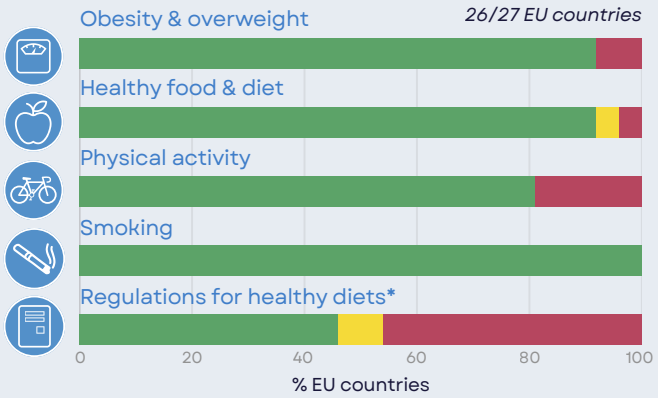
€3,500

DIABETES PREVENTION

Yes | With variations | No

One of the key pillars of T2D prevention is the implementation of **health-enabling policies**. Across the EU, more needs to be done for these to be fully implemented. At least one country, rising to 12 countries for regulations for healthy diets, do not have those in place.

**Regulations for healthy diets include binding measures such as sugar taxes and bans on advertising unhealthy food and beverages to children.*



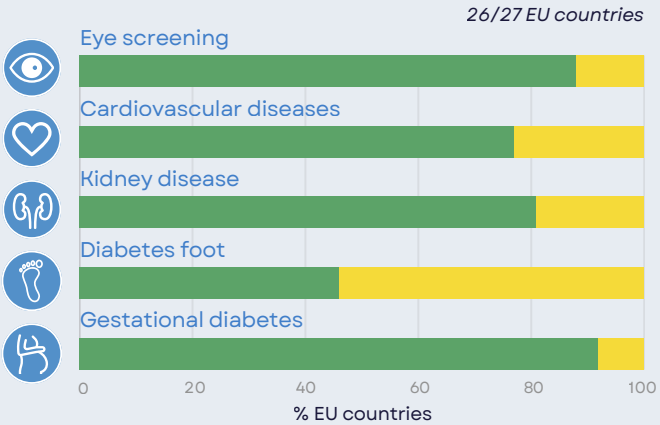
DIABETES MANAGEMENT

Yes | With variations

Diabetes management has one main objective – lowering the risk of acute and chronic diabetes-related complications, while maintaining the highest possible quality of life. This is achieved through controlling glycaemic levels and managing co-morbidities as well as through preventative approaches aiming to prevent organ and tissue damage. A prerequisite to effective diabetes management is access to the medicines and technologies required to control blood glucose levels and other risk factors and administer medicines as well as self-management education and an integrated, person-centred and personalised approach to care.

Regular **screening** is essential to identify potential complications early and prevent their progression.

Screening for complications



Psychological support is a key component of diabetes care and management. However, PwD in about 24 EU countries do not have full access to psychological support due to a lack of specialised HCPs and/or the cost of services not being reimbursed.

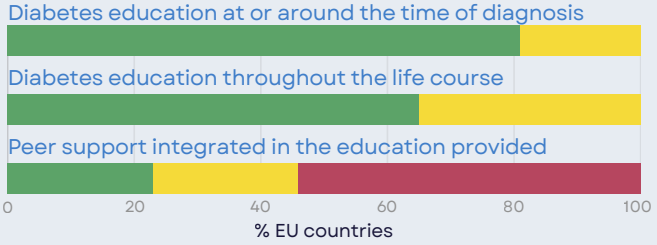
DIABETES MANAGEMENT

Yes | With variations | No

Diabetes is a chronic, life-long and incurable disease. Its management is highly complex, with the need to balance nutrition, physical activity and medication (often poly-pharmacy), 24/7. The vast majority of people living with T2D are treated in primary care, with limited support from healthcare professionals, which they may see only 2 or 3 times a year. People living with T1D or on insulin treatment may have to make an extra 180 decisions a day. Self-management is therefore a crucial element of diabetes management.

Self-management education

26/27 EU countries



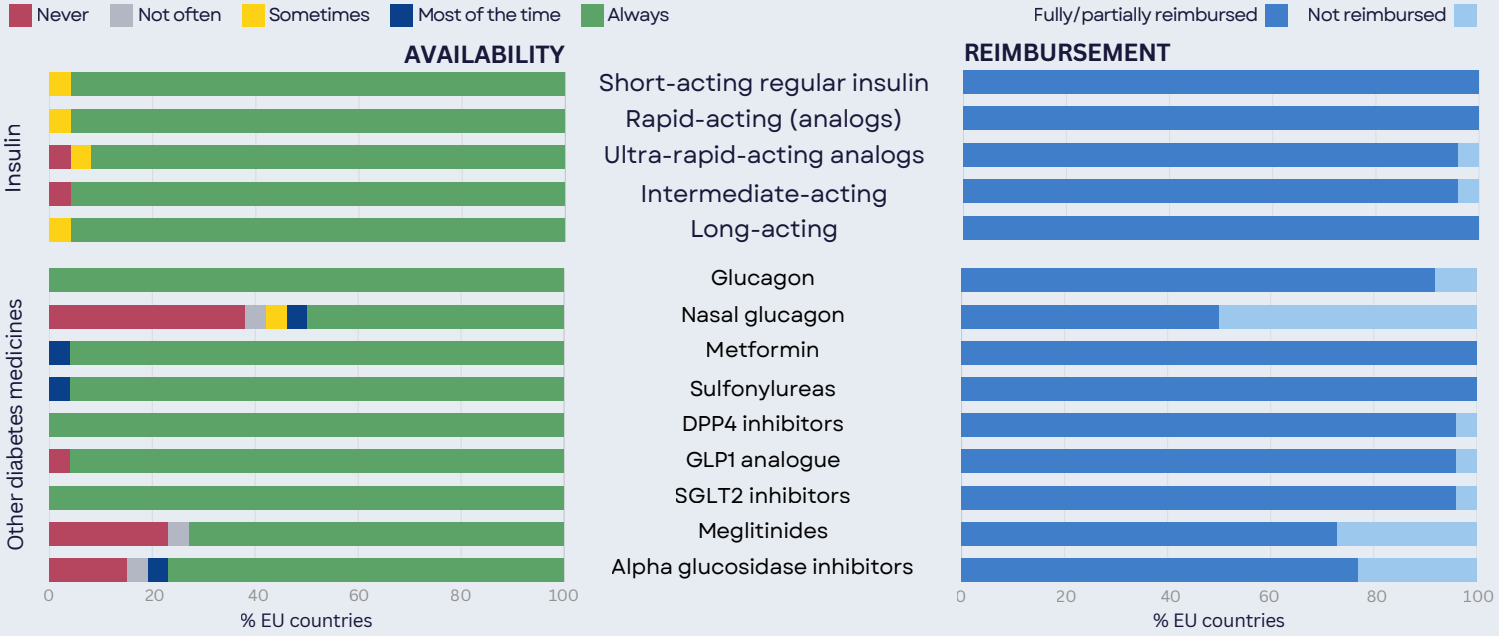
Self-management education is not provided systematically in at least five to nine EU countries.

Peer support is effectively integrated in diabetes education in six countries.

ACCESS TO MEDICINES, TECHNOLOGIES AND SUPPLIES

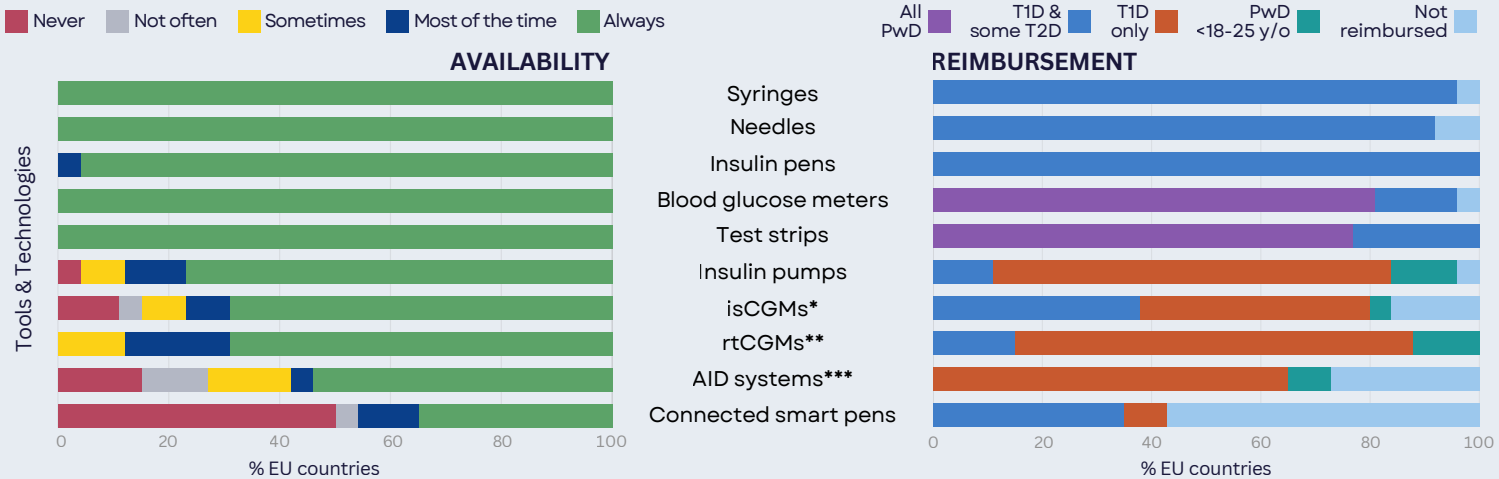
26/27 EU countries

Access to medicines is generally not an issue in EU countries, although shortages do occur, both for basic products such as insulin, as well as for newer medicines, such as GLP-1s. Affordability is subject to more variability.



PwD must check their blood glucose several times throughout the day and adjust their treatment accordingly. Access to reliable tools for monitoring blood glucose is therefore crucial for managing their condition effectively and preventing life-threatening complications.

In the past, blood glucose monitoring tools have largely been reserved to people living with T1D or on intensive insulin treatment. Recent studies have demonstrated the benefits of tighter control for people on once-daily insulin treatment as well as those on oral medications, and several EU countries have extended their provision of glucose monitoring tools.



*Intermittently-scanned continuous glucose monitors

**Real-time continuous glucose monitors

***Automated insulin delivery systems

HEALTHCARE SYSTEMS READINESS

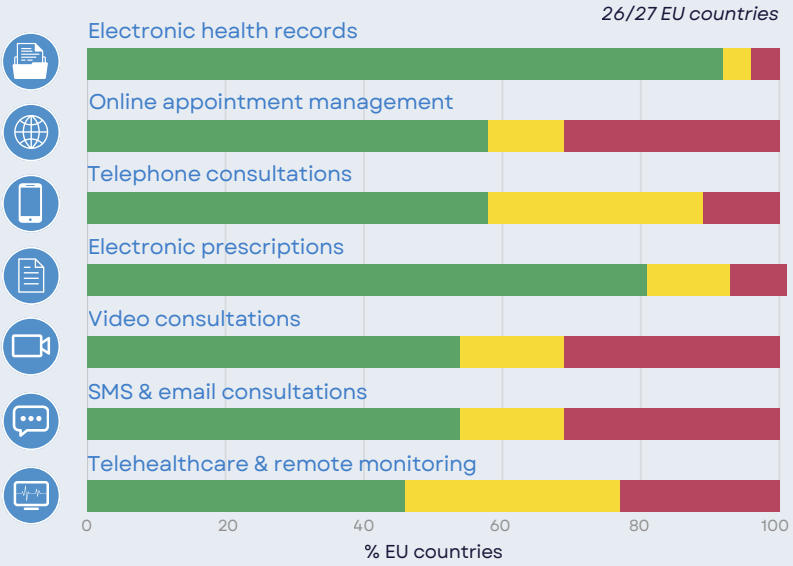
E-health services

Yes | With variations | No

Novel approaches to the delivery of care supported by digital tools such as web portals, apps, telemedicine and digital therapeutics can be used to improve diabetes management, facilitate interactions between PwD and HCPs and support access to information.

Only about nine EU countries provide systematic access to a wide range of e-health services for all PwD.

Apps to prevent/manage diabetes are recommended in about 18 EU countries but they are only sometimes reimbursed in four countries.



National Diabetes Plans

National Diabetes Plans are comprehensive frameworks developed by governments and health authorities to address the growing burden of diabetes within countries. They typically include diabetes prevention and treatment strategies, but they can also incorporate strategies on early diagnosis, routine care, reduction of complications, support for research and innovation, and PwD education. NDPs can be stand-alone and address diabetes specifically or as part of broader NCD strategies.

YES

Stand-alone **In some reagions*

- Croatia
- Czechia
- Finland
- Greece
- Italy*
- Malta
- Netherlands
- Portugal
- Romania
- Slovakia
- Slovenia

Partly integrated

- Austria
- Cyprus
- Poland

Fully integrated

- Spain

UNDER DEVELOPMENT

- Belgium
- Estonia
- Hungary
- Lithuania
- Luxembourg

NO

- Bulgaria
- Denmark
- France
- Germany
- Ireland
- Latvia
- Sweden

NDPs should be tailored to the unique context of each country to ensure that interventions are relevant and effective in providing person-centred care for all PwD. NDPs should also include monitoring and surveillance mechanisms to facilitate data collection on their implementation and measure the effectiveness of diabetes-related interventions.

National Diabetes Registries

National Diabetes Registries (NDRs) enable the systematic collection of data about PwD and their care. They are typically used to monitor PwD's health outcomes and/or the performance of diabetes care over time. NDRs can include detailed information about PwD demographics, medical history, treatment plans, laboratory results and outcomes related to their diabetes care and management.

YES

- Croatia
- Denmark
- Finland
- Latvia
- Sweden

FOR SELECTED GROUPS*

- Austria
- Belgium
- Czechia
- France
- Germany
- Hungary
- Ireland
- Italy
- Luxembourg
- Netherlands
- Poland
- Portugal
- Romania
- Slovakia
- Slovenia
- Spain

**Age, diabetes type, treatment*

NO

- Bulgaria**
- Cyprus**
- Estonia
- Greece
- Lithuania
- Malta**

***Under development*

NDRs are essential tools for HCPs, researchers and policy makers to ensure the availability and provision of high-quality diabetes care based on personalised and data-driven decision making.

TRANSFORMING THE DIABETES JOURNEY –
adopting a life course approach for citizens' improved well-being and healthcare systems' resilience in the European Union

SOURCES:

1. IDF Diabetes Atlas 2024: https://diabetesatlas.org
2. Statista: https://www.statista.com/statistics/241831/health-care-costs-due-to-diabetes-worldwide-by-region/
3. The Lancet: https://www.thelancet.com/journals/landia/article/PIIS2213-8587(17)30097-9/abstract
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IDF Europe is the European chapter of the International Diabetes Federation (IDF). We are an umbrella organization representing 75 national diabetes organisations in 46 countries across Europe. We are a diverse and inclusive multicultural network of national diabetes associations, representing both people living with diabetes and healthcare professionals.

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